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Understanding the outcomes of specialist nursing:

Supporting Carers of People with Dementia

A mixed methods evaluation and feasibility study (January 2018)

Unpaid carers are the mainstay of the UK care system for people with dementia. Yet caring can have an impact on the well-being and health of the carer.

Admiral Nursing is the only specialist nursing service in the UK that specifically focuses on supporting carers of people with dementia, but evidence of its effectiveness, costs, and relationships to other services is limited. This project aimed to address this gap and explore the feasibility of full-scale formal evaluation.


The aims of the research

Unpaid care can be provided by partners, family, friends or neighbours. Through this research we aimed to:

- 1) Understand more about who uses Admiral Nursing services, how the services operate and what we can learn about outcomes from the existing Dementia UK database
- 2) Hear, from the perspectives of unpaid carers themselves, what outcomes are influenced by the support they receive, and what happens when support is absent or of poor quality
- 3) Develop and test data-collection methods for future cost-effectiveness research incorporating the outcomes prioritised by carers
- 4) Explore the cost-effectiveness of Admiral Nursing, as against usual care, through a survey of carers in 34 areas of England
- 5) Explore the perceived system-wide impact of support for carers of people with dementia

Overview of findings

From the existing data we saw that Admiral Nurses are successfully targeting the most complex cases and, on average, the needs of carers being supported by Admiral Nurses reduced over time. However, we did not have the right information to link this reduction to the activity of the Admiral Nurses.



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Findings from a qualitative study

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<https://www.york.ac.uk/spru/projects/admiral-nursing/>

Aims and background:

- ◆ Wider study aimed to evaluate support for **carers** of people with dementia (Admiral Nursing as an exemplar)
- ◆ Qualitative interviews to **identify outcomes to measure**

What is Admiral Nursing?

- Specialist nursing service for carers of people with dementia (**unique in the UK**)
- Case-management approach
- Has not been externally evaluated on a large scale before



Service website <https://www.dementiauk.org/how-we-help/admiral-nursing/>

Interviews and focus groups

Aim of qualitative strand:

- Outcomes of support from Admiral Nursing (AN) and other services
- Outcomes of *not* getting support
- How can we measure these?

35 carers of people with dementia:

- Interviewed *or* took part in a focus group
- 18 with AN
- 17 from areas without AN

Topic guide asked about the outcomes of:

- Information and advice
- Assessment/review of carers' own needs and of the person with dementia
- Financial support
- Training
- Help in the tasks of caring
- Emotional support
- Support to remain in/take up paid work



Key theme: Confidence in caring

Interviewer

What ultimately ... is the result or outcome of you having this Admiral Nurse?

Um, I think confidence is a lot of it, confidence that I can get help, confidence that I'm not alone, there's someone out there to help, who fully understands and who is trained in the specific illness.

Carer with Admiral Nurse [AN2C7]

Selected measure of confidence

Carergiver Self-Efficacy for Managing Dementia scale

(Fortinsky, R.H., Kercher, K. and Burant, C.J., 2002.

Measurement and correlates of family caregiver self-efficacy for managing dementia. Aging & Mental Health, 6(2), pp.153-160.)

Covers (for e.g.):

- Confidence in ability to handle any problems person with dementia has
- Certainty that you can find answers to questions about the disease
- Confidence to face the future



Confidence in ability to handle problems

I just think I feel lost, because we've got a situation and I think I don't know how to handle this... At times I just feel I just don't know where to turn and what to do...

Carer without
an Admiral
Nurse
[NAN2C6]

... it'd be nice for [there to be] somebody that, once you are diagnosed, they know you, [and] the person with it, and come and see you ... and as the illness progresses and deteriorates, you have this support that "Have you tried this?" or "Have you tried that?"

Certainty that you can get answers to your questions about the disease

Carer without Admiral Nurse [NAN1C1]

...once the illness takes over ... the support isn't always there, I've been trying for long enough to have the psychiatrist check my wife's illness and tell me, because I, I actually don't really know what stage she's in and I seem to be having quite a bit of problem of getting the doctor to look at my wife, to be honest

Getting answers about the disease

The thing about the Admiral Nurses is ... my mum would do something really random and I'd think "Is this part of it? Is this part of the disease, is this how it works?" They always, always had time to speak to me.

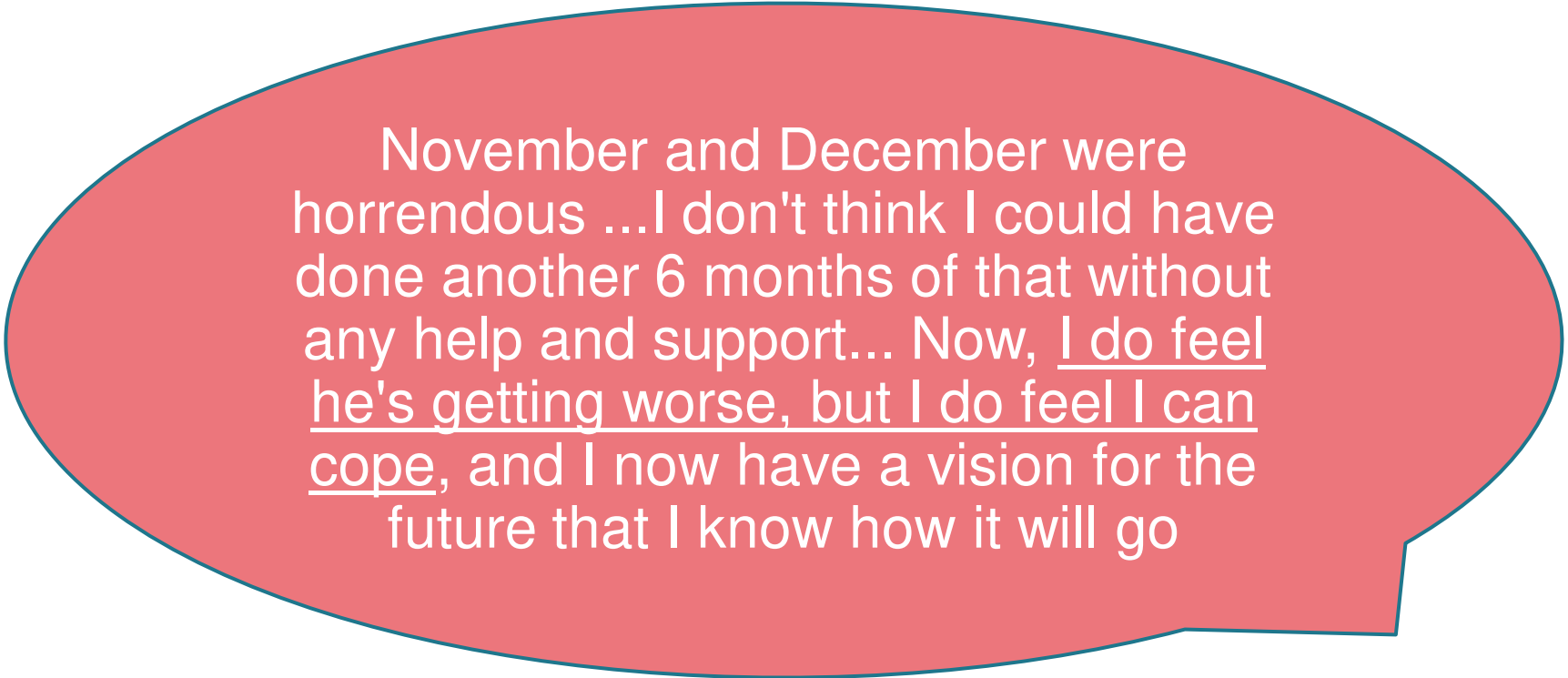
P1

They always know what to say.

P2

They just calm you down, and explain in a fashion that you understand.

Certainty that you can handle problems that might come up in the future



November and December were horrendous ...I don't think I could have done another 6 months of that without any help and support... Now, I do feel he's getting worse, but I do feel I can cope, and I now have a vision for the future that I know how it will go

From Focus Group 2 in Admiral Nursing Area 2

But 'confidence' doesn't cover everything....

Carer Quality of Life

Selected measure:

ASCOT-carer (Rand, S.E., Malley, J.N., Netten, A.P. and Forder, J.E., 2015. Factor structure and construct validity of the adult social care outcomes toolkit for carers (ASCOT-carer). *Quality of Life Research*, 24(11), pp.2601-2614.)

Covers (for e.g.):

- Isolation and control over your time
- Safety and self-care
- Feeling supported (the only measure that had this as an outcome in itself)



Isolation and control over your time

...it's like you're in this little bubble that he doesn't want anybody [else] to be in ... [and] I cannot make a choice to go out anywhere ...'

P1 ...you become isolated with that person you're looking after...

Carer without Admiral Nurse [NAN2C7]

P2 For me that's the biggest thing...

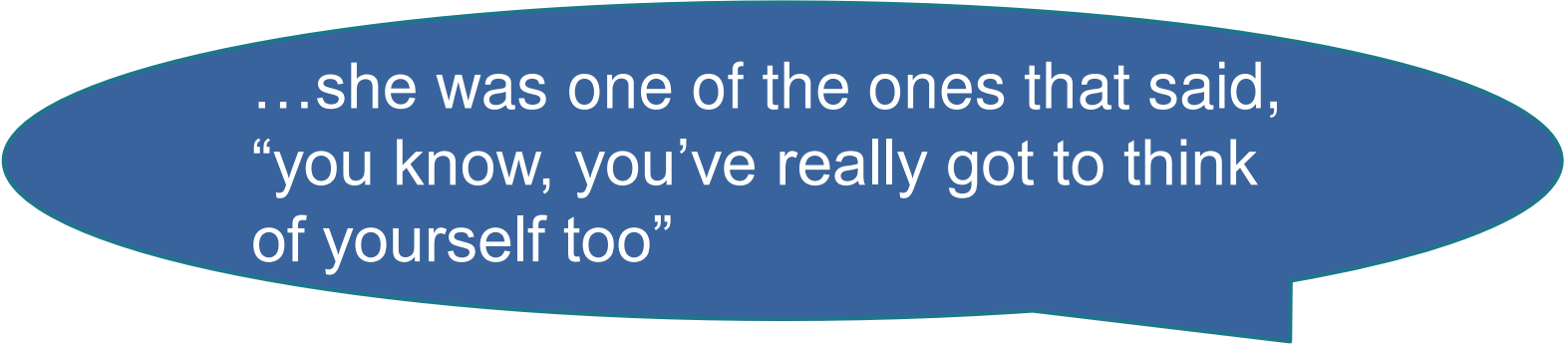
...that can lead to carer breakdown so quickly...

P3

From Focus Group 1 in Non-Admiral Nursing Area 2

Safety and self-care

- ◆ Examples of carers' health (mental and physical) suffering from self-neglect
- ◆ Examples of physical threat
- ◆ The Admiral Nurses' focus on the wellbeing of the carer could help carers to recognise unsafe situations:



...she was one of the ones that said,
“you know, you’ve really got to think
of yourself too”

Carer with Admiral Nurse AN1C5

Feeling supported

I said to her “Just knowing that you’re coming every month.” Because things change with [wife], and when they change they change quickly, so ...it’s almost like a comfort blanket, you know someone’s coming.

Carer with Admiral Nurse AN2 Joint

It's two fold, they know you really well, but they're not in it... they can see what it's doing to you, they can see what you need, even when you can't yourself, and they can encourage and guide.

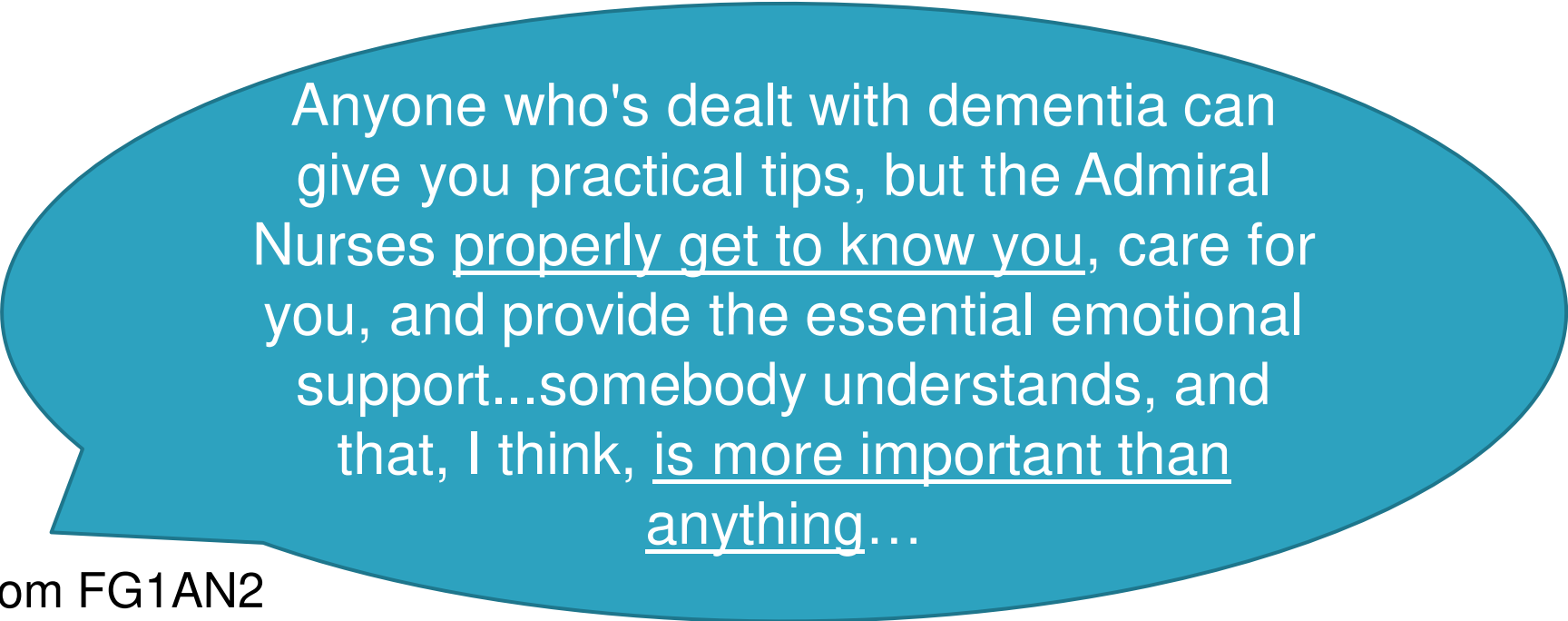
From Focus Group 1 in Admiral Nursing Area 2

In summary:

Outcomes: **1. Confidence in caring** (Carergiver Self-Efficacy Scale)
2. Carer Quality of Life (ASCOT-Carer)

Key contributors:

1. Support coming from a **specialist** in dementia
2. This specialist offering **continuous** support and
3. Invests the **time** to get to know the families well



Anyone who's dealt with dementia can give you practical tips, but the Admiral Nurses properly get to know you, care for you, and provide the essential emotional support...somebody understands, and that, I think, is more important than anything...

Echoes previous York findings:

1. Factors promoting continuity of care for people with long-term neurological conditions <https://www.york.ac.uk/spru/projects/nsf-ltnc/>

1. a single person or team co-ordinating support across boundaries
2. this person or team having specialist knowledge (of the disease and of available systems of support)
3. flexibility in how, when and where support is delivered
4. long-term involvement
5. proactive monitoring and/or follow-up



2. People with complex needs <https://www.york.ac.uk/spru/projects/complex-needs/>

'It was strongly felt that ongoing access to a designated key worker or case manager with specialist knowledge could improve access to, and continuity of, support.'



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